

# What have people been telling us?

A summary of our evidence - July to September 2019

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## An overview

Between July and September 2019, thousands of people shared their experiences of using health and social care with Healthwatch. This quarterly briefing aims to provide health and social care professionals with a summary of the issues people have raised with us.

Each publication takes an in-depth look at people's experiences of a specific area of care, and at what people from particular sections of society think of services.

### Where does our evidence come from?

This briefing is informed by over 10,500 people's views, drawn from 128 local Healthwatch reports about NHS and social care services, as well as an added 3,500 items of individual feedback from the public.

### What issues do we look at?

#### Emerging themes across health and care

<i>Primary care</i>	The poor communication of GP practice mergers and closures has resulted in some people being deregistered and unable to access support.
<i>Hospital care</i>	People's physical health concerns are not always being taken seriously if they also have a mental health condition.
<i>Social care</i>	People face long waiting times when it comes to getting assessments for autism support.
<i>Mental health</i>	Patients, families and carers report not being involved in decisions about people's diagnosis, treatment and support.

#### In focus: Continence care

We look at the support available for people with incontinence and how services can help by making sure patients can easily access the continence products they need.

#### Spotlight on experiences: Diverse ethnic communities

Find out what people from different ethnic communities have told us about the challenges they can face when using health and care.

# Issues across health and care

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# Primary care

2,740 people's experiences informed this section

## General practice

### Emerging issue: Poor communication about service changes

When services change, it is important that these changes are communicated and do not affect people's care. Our evidence suggests this is not always happening, especially when people have been deregistered by their GP or when GP practices are closing or merging.

Across the country, people have told us they have received letters telling them they have been deregistered because:

- they have moved out of the GP catchment area or the catchment area has changed so their address is no longer included in it.
- they have not visited their GP in over two years.

When someone is deregistered from their GP practice they can be left without support. This can lead to people using already pressured urgent or emergency care services instead.

#### Personal story: Deregistered despite my complex needs

"A woman is moving to a new home out of the catchment area for her current GP. She wishes to remain with the surgery as she has complex medical needs, however the surgery has said they will deregister her when she moves. She and her family are very unhappy about this and contacted Healthwatch to find out if there was anything else they could do."

Healthwatch County Durham

People have also told us that they are concerned that the merging or closure of GP practices will affect the quality of care they receive from their GP. Again, services must communicate any changes happening and the effect it will have on patients and give people information about how to use other services. The experiences people have shared with us suggest that this is often not happening and, as a result, they are unable to access support.

## What can staff do to provide a better experience?

To help prevent these issues, GP practices must (a) communicate the reasons for any changes (b) make sure the reason someone has been deregistered is appropriate (c) tell people how to access support when they have been deregistered.

### Ongoing issues

<p><i>Problems getting appointments</i></p>	<p>We continue to hear about difficulties with booking appointments due to limited availability, with some people waiting up to two weeks to see a GP.</p> <p>If services cannot increase the number of available appointments, they can help by making sure that other issues, like being unable to get through to staff on the phone, having appointments cancelled or complicated booking systems, are looked at to reduce the frustration people feel.</p>
<p><i>Unable to see the same professional</i></p>	<p>People continue to tell us that continuity of care can be an issue, as they are often unable to see the same GP or nurse unless they are prepared to wait a long time for the next available appointment.</p> <p>This means people must explain their health issues over and over again to healthcare professionals who do not know their health history.</p>
<p><i>Staff attitudes</i></p>	<p>The attitudes of receptionists, doctors and nurses can have an impact on people’s experiences of GP services. People often leave feeling 'dismissed' without being given the information they need.</p> <p>Services can help by making sure staff communicate with people in a friendly, caring and helpful manner.</p>

## Dental and pharmacy services

### Ongoing issues

<i>The unexpected cost of dental care</i>	People are unsure if they are eligible for free dental care, resulting in disputes with services. Some have been unexpectedly charged when they should not have been. For people with limited income, this has caused unnecessary stress and made it harder for them to look after their health.
<i>Difficulty getting an NHS dentist</i>	Finding an NHS dentist is hard for people in some areas, which can result in people paying privately for dental care, which can be very expensive.
<i>Unavailable or incorrect prescriptions</i>	People continue to tell us they have been given the wrong prescription, their medicine has gone missing or they haven't been given enough medication.

### What can staff do to provide better information?

A review of the questions people are asking us indicates that primary care services could improve people's experiences by providing better information about (a) how people register with a service and (b) how people can complain.

# Secondary care services

2,950 people's experiences informed this section

## Urgent and emergency care

### Emerging issue: Physical symptoms being attributed to mental health

When people attend A&E it's important that their mental and physical health are given equal consideration.

However, this doesn't always happen, and people tell us they have experienced physical health concerns being wrongly attributed to a pre-existing mental health condition, such as anxiety. This can be frustrating and has seen people have to push for further tests or support, as healthcare professionals have seemed slow or unwilling to take them seriously.

#### Personal story: It's your anxiety

"I had an ambulance out about two months ago for severe chest pains and pains down my arms, they put it down to anxiety. Two months on, I am currently curled up in pain, in agony with chest pains, getting dizzy to the point of nearly passing out. I went [to a hospital] where he heard about [my] anxiety and instantly brushed me off, refused to give me any scans or even consider the possibility I might actually be very ill, so now I'm sat at home, shortness of breath, in absolute agony."

Healthwatch Rochdale

### Ongoing issues

<i>Long waiting times</i>	Feedback about waiting times is often negative, with some people choosing to go home and look after themselves, rather than wait. Others feel frustrated that their concerns over waiting too long had not been taken seriously.
<i>Uncomfortable waiting times</i>	Long periods in unstimulating waiting rooms with uncomfortable seating and no refreshments can be hard for people who are ill or hurt.



## Hospitals

### Ongoing issues

<p><i>Barriers for people who are deaf or hearing impaired</i></p>	<p>People who have a hearing impairment tell us that services do not meet their needs. Often there is no interpreter available, making it hard for people to understand what healthcare professionals are telling them. This can be frustrating and upsetting if they receive advice or a diagnosis without someone to translate. People also tell us that some appointment systems only allow them to cancel using the phone. This can add to someone's already negative experience if they have been unable to get an interpreter.</p>
<p><i>Parking problems</i></p>	<p>People commonly report that when they cannot find a parking space, they have to walk a long way from their car to the hospital and have to pay expensive car parking charges. This can affect their experience of care, especially if they have mobility problems or a condition that demands long or frequent visits to the hospital. Some people tell us that they have missed or have had appointments cancelled because they haven't arrived on time.</p>

### What can staff do to provide better information?

A review of the questions people are asking us indicates that secondary care services could improve people's experiences by providing better information about (a) what to do if someone has to wait a long time for an appointment or treatment (b) what to do if an appointment gets cancelled after waiting a long time (c) the support available after discharge, and (d) how people can complain.

# Social care services

1,910 people's experiences informed this section

## Emerging issue: Support for autistic people in social care

Social care support for autistic people covers a wide range of services, such as community care or funding support, but often people's experiences are poor. For example, it can be hard to get an assessment for support and people can face long waiting times for assessment appointments. Information the NHS provides about [interim support](#) shows people can expect long waiting times for these services as well.

Eligibility criteria can also cause people distress if they do not qualify for support or even an assessment, so they can access services. Meeting diagnostic criteria can be especially hard for girls, as growing evidence suggests that their autism can present differently. Many girls and young women are therefore able to 'mask' autistic behaviours common in boys and, as a result, are more likely to be misdiagnosed and left without support.

### Personal story: Not eligible for an assessment

"A woman is trying to access an assessment to confirm her daughter's autism with the local paediatric unit. She was given a sheet to fill out in preparation for the assessment to see what autistic traits her daughter had. After filling in the form, she was told that her daughter didn't meet the requirements to be assessed for autism, meaning the Clinical Commissioning Group will not pay for the assessment to be done. Her daughter is managing to hide her symptoms well at school but when she comes home she is acting out and slapping herself in the face out of frustration."

Healthwatch Essex

### What can staff do to provide a better experience?

To help deal with these issues, staff can make people aware of what they should expect when it comes to the assessment and diagnosis of autism. To help to communicate this information to young people, the National Institute for Health and Care Excellence [has produced a guide](#).

### Ongoing issues

<p><i>Inconsistent care</i></p>	<p>The feedback we receive about care homes is mostly negative and relates to inconsistent care. Services can improve people’s experiences by delivering high quality and personalised care, which is planned and developed with residents and their family and carers.</p> <p>People tell us that choice is especially important in helping them to feel in control and that consistently good care makes a big difference.</p>
<p><i>Lack of staff empathy</i></p>	<p>People tell us that staff ignore complaints and requests from residents and their families, particularly in domiciliary care and care homes. People don’t always receive empathetic care, which can be caused by understaffed teams trying to deliver the same standard of care.</p>

### What can staff do to provide better information?

A review of the questions people are asking us indicates that social care services could improve people's experiences by providing better information about (a) what support is available for autistic people (b) how people can get respite care and (c) how people can get home adaptations or equipment.

# Mental health services

Nearly 4,500 people's experiences informed this section

## Emerging issue: Getting the right mental health diagnosis

Getting the right diagnosis for a mental health condition is important, as it affects the treatment and support someone is offered. However, people have shared with us that they have not been consulted about their diagnosis, sometimes leading to a misdiagnosis or disagreement between the healthcare professional, the patient and their loved ones. This is particularly the case for families and carers of people with a mental health condition, who have shared that they have not been involved in assessments, diagnostic consultations or decisions about the support offered to the person they care for.

### Personal story: Struggling to get a referral

"My child, who is now 11 [was] referred to [CAMHS] for ADHD treatment back in 2018 after many failed attempts to obtain a diagnosis... The appointments we have had with consultants have been less than satisfactory... We have often felt patronised and not listened to... My other son who has ASD was referred a few times for mental health problems related to his disorder. Each time we have been rejected as apparently he does not meet the criteria. We feel this is unacceptable, to provide vulnerable children and their parents with no specialist help."

Healthwatch Bucks

## What can staff do to provide a better experience?

Services can help [by following guidance](#) from the National Institute for Health and Care Excellence. The guidance explains what people should expect when using NHS mental health services, from when they are first referred, to what should happen during an assessment and how people should be involved in their treatment.

## Ongoing issues

<i>Families and carers want to be involved in their loved one's care</i>	People's mental health problems can affect their families, friends and carers. As a result, families and carers regularly tell us they would like to be involved in their loved one's care.
<i>Long waiting times for mental health support</i>	Adults, children and young people continue to complain about the long waits for mental health services, both for initial assessments and further support.
<i>Effect of positive staff attitudes</i>	People tell us that healthcare staff who act in an understanding, helpful and professional manner can have a profoundly positive effect on their mental health and experiences of care.

## What can staff do to provide better information?

A review of the questions people are asking us indicates that mental health services could improve people's experiences by providing better information about (a) what mental health support is available to people (b) what support is available for autistic people and people with a learning disability and (c) how people can contact home treatment teams.

# In focus



# Continence care

194 people's experiences informed this section

## Who is affected?

Incontinence, a condition that causes involuntary passing of urine and/or faeces, affects [approximately 14 million people](#). If you are older, especially if you have a cognitive impairment or dementia, you are more likely to experience incontinence.

Continence problems can have a profound impact on someone's dignity, health and independence. As many people often feel too embarrassed to seek help, more people may be affected by incontinence than is reported.

Incontinence issues are sensitive for many people, they should get support that preserves their privacy and dignity. When people have negative experiences of care it can prevent them from seeking future help, which can lead to difficult circumstances for both patients and healthcare professionals.

## What can services do to improve people's experience of support?

Healthcare services can provide good continence care by making simple changes that are proven to work. Based on the feedback we received, services can help by (a) making access easy, with clear and discrete signposting and advice available (b) ensuring the products they provide are high quality and the supply meets an individual's needs and (c) being empathetic and helping to maintain a person's dignity.

## What have people told us?

Although the number of people who have shared experiences with us about continence care is relatively small, their views have been overwhelmingly negative. Most people are not receiving help that meets their needs or they are simply unaware of the support available to them.

### Problems accessing continence products

People have told us they often face difficulties receiving adequate continence care and that this can limit their independence. Issues people have faced include:

- Not being able to find information on how to access continence support.
- Long and complicated processes for getting continence products or care reviews.
- Being unable to arrange automatic or repeat orders of continence pads. This is a particular issue for people with memory impairments, who might forget to place an order in time.
- Waiting up to two weeks to receive products once ordered.
- Having to pay for expensive continence pads themselves while they wait for products or because services don't provide them. As a result of these issues, or continence budgets being reduced, we have heard that some people are spending over £100 per month on supplies. This is especially difficult for those on a low income.

#### Personal story: Ordering continence products

"I am an elderly patient with memory and incontinence problems. I get nurses to come home to support with incontinence and to provide pads, but I need to remember to book them to come regularly. I have memory problems, so this is really difficult for me to do, as a result I end up having to pay for pads that I cannot afford. I have asked if they could make the appointment automatic, but I was told they don't do that. They have refused to help me with this problem."

Healthwatch Birmingham

#### Products not meeting people's needs or being of poor quality

People do not always have enough continence products, or they are not the right type or size for them, leaving them embarrassed and upset because of pads that don't fit. What we hear is that people receive pads that are ill fitting or leak, which affects their hygiene and dignity.

Good quality continence products help avoid complications, such as:

- urinary tract infections that lead to people feeling confused, particularly in older age, increasing their risk of falls and fractures.
- pressure ulcers caused by prolonged exposure to moisture.

#### Personal story: The impact of poor-quality products

"The contract for incontinence pads has changed and the replacements are 'awful'. A number of carers are infuriated by this and their stories show how such a simple thing can have such a huge impact on basic day to day life. One person reported their daughter may not be able to go to school if the pads aren't changed back to workable ones. Carers



also talked about being unable to leave the house and there have been some horrific comments from the incontinence team, such as 'limit her fluids, you can always pick the poo out of the pad and keep using the pad'. They apparently rip, leak and don't fit properly."

Healthwatch York

## What can services do to help people dispose of products?

People should know how to safely dispose of continence pads. Services can help by (a) providing accurate advice on how to dispose of continence products (b) make it clear how people can return unused continence pads when someone has died, and (c) consider how changes to the frequency of local council bin collections can result in overflowing and unhygienic bins.

## Issues with empathy and mental health support

People who use continence services can feel depressed or defeated when they are unable to continue their normal routines and it can be difficult for people and their loved ones to adjust their lives around incontinence. In some instances, people have stopped eating and drinking because they have been worried about continence accidents.

### Personal story: Maintaining social independence

"I would describe his mental state as despair/depression/resignation and seems to be totally unaware of any help or support or options open to him... [He has] incontinence issues which means he is almost always wet and completely distressed about it and feels unable to maintain social contact and this is obviously also affecting his wife."

Healthwatch Essex

NHS guidelines state that it is essential for staff dealing with people with incontinence to provide care with empathy. However, people have told us that they have not always received compassionate care and services have responded inappropriately when they have voiced their concerns.

Healthwatch Sefton found home care staff had been advised by the continence service to restrict residents' drinks as a solution to requiring more pads, which can cause people serious physical harm, particularly if they are older. People have also been told by continence teams to reuse soiled pads if they had a shortage. In other instances, people have been denied products but not told why.

When people have complained about these kinds of issues, services have not responded to them or there has been no improvement to their care as a result.

**Personal story: Providing empathetic care**

"A woman received a letter from the incontinence clinic that they were changing their supplier for the continence pants, but it was to be a like for like change and her husband would not be affected. However, when the new contract was in place her husband received pads and not pants. As a result, her husband has no dignity while using the pads as they slip, and he is constantly wet and soiled. After contacting the incontinence clinic she was told that the pants were not being supplied anymore even though she was told that the change was on a like for like basis. She then rang the office that deals with the incontinence pads to be told that she can buy the net pants to hold the pads in place at the chemist, but she cannot find a chemist that sells them."

Healthwatch Wakefield

**Disabilities not being considered**

Disabled people who require continence services often need more support. The NHS aims to provide personalised care for people with complex needs, but the feedback we've received suggests that services are not providing even basic support for some people.

For example, one person with spinal paralysis was discharged from the continence clinic because their GP had not referred them in time. This meant they had to buy the pads themselves despite being unemployed because of their disability. In another case, an individual had to wait longer for continence support because the GP did not correctly list their disabilities.

**Personal story: Taking away independence**

"A woman called Healthwatch, as she wanted to make a complaint about the treatment her daughter received, who is 19 and has a learning disability. She has continence issues which she was independently managing using 'pull ups'. Since coming to the UK from Australia she has been assessed by the continence team who have 'prescribed' her pads. Her mum asked for 'pull ups' and was told that she can't have them. Her daughter is unable to use the pads independently, hence she has had her independence taken from her."

Healthwatch Cheshire West

**Poor support in care homes**

Incontinence is often a reason why older people are admitted to a care home and while living there they are entitled to the same level of support from NHS continence services as those living in their own homes. However, what we hear is not always positive.

People have told us they have been left in wet or soiled pads because of a shortage of care home staff or staff not taking them to the toilet frequently enough. Family and carers have also had to pay for pads when residents have not been given appropriate continence products.

Attitudes of some care home staff have also shown a lack of empathy and compassion. In some instances, they have asked people to pay more if they want better care, not responded to people's concerns or have not considered people's individual needs when providing care.

## Our findings within the wider context

We look at how external research and guidance for services fits with what people are telling us.

### The wider evidence

Three [National Audits of Continence Care](#), conducted between 2005 and 2010, found evidence of widespread rationing of continence products, people not given routine assessments, and regional variability in care and service delivery.

The full national audit has not been recommissioned since 2010, meaning that we have no national evidence about whether continence care has improved.

However, people's experiences and wider evidence suggests that the problems have not gone away.

Earlier this year, [the results](#) of a small-scale qualitative study on continence pad provision found that patients' needs are not being met, while a 2018 [report](#) from ten charities highlighted the inconsistency of support for incontinence and gaps in access to knowledge around non-clinical management of incontinence issues. A 2017 [survey of care home staff](#) found that 26% of care homes were forced to ration equipment like continence pads, with staff sharing stories of how they were forced to resort to re-using pads.

### Availability and access of products

Experiences shared with Healthwatch point to recurring issues around access to continence products, insufficient volume of products available, as well as problems with their quality and suitability.

Currently, there is no statutory requirement for the provision of pads for incontinence, meaning that each commissioning organisation develops its own approach. The NHS and other organisations have produced national guidance around best practice in continence care, but it is not binding, resulting in the varied and uneven provision of care.

A 2017 [guidance document](#) from the Royal College of Nursing (RCN) and the Association for Continence Advice (ACA), which was supported by the NHS Excellence in Continence Care programme, states that “the number of absorbent pads issued per 24 hours would normally not exceed 4, but provision should meet assessed clinical need”. Though the suggestion of a daily ration is qualified through the note about clinical need, using national guidance to specify a possible daily ration sets an expectation for commissioners, which puts numbers first and patient needs second.

If commissioners or services are rationing products to cut costs, they run the risk of creating a false economy that creates short-term savings but costs the system more in the long run.

In its 2015 guidance, NHS England acknowledged: “Over the years, some excellent research and guidelines have been produced for best practice continence care, but this work has often stalled as it has not translated into a clear commissioning plan for local continence pathways”.

An [update to this national guidance](#) published in 2018 sets out a positive vision of what good care looks like, but with no statutory requirement and little national data about service quality, it is impossible to know how it is being implemented.

## Reviewing people’s needs

The RCN and ACA guidance states that “reassessment of product provision should be undertaken annually as a minimum”. Yet we know that even where reassessment is a statutory requirement, services are often not meeting their responsibilities. For example, our [July 2019 report](#) found that only half of those using social care services received the planned review they are entitled to in the preceding year.

The 2018 [Excellence in Continence Care](#) document agrees that “there appears to be no consistency as to the frequency of continence assessments.” Several of the negative experiences shared with us indicate that people are unable to access a review of their continence care needs, even where they have requested it.

It is the responsibility of the health service to ensure that national eligibility thresholds are meeting people's needs and that reviews and reassessments are conducted in a timely fashion. The assessment and review process should also minimise barriers for those who have recurring needs. If someone has been appropriately assessed, delivery of continence products should be automatic unless a scheduled review identifies a change in their needs.

If someone’s condition improves, they should be able to lower the amount of continence products they order or pause their order but have the option of returning to their previous level of provision without having to go through a difficult re-assessment process.

## Emergency provision of continence products

Currently, people can only receive continence products through the NHS once they have been through an assessment. The RCN and ACA guidance states that “individuals should self-fund absorbent pads until an assessment has taken place”.

Yet current [NHS guidance](#) estimates the monthly cost of pads as £34-73 for daytime use and £43-£64 for night-time use. By the NHS's own estimates, someone who needs continence products all the time could be spending up to £137 each month. This sum could be a significant financial burden while someone is going through an assessment process.

It is not clear how long a typical continence care assessment process should take, but it may be weeks or months until people get NHS continence products. National guidance says that steps should be taken to treat and address factors contributing to incontinence to minimise the use of pads, implying that the provision of continence products should be a last resort. Nursing Times [has reported](#) on examples of patients not being offered any containment products until they have tried alternative exercise or treatment regimes.

Not only do lengthy assessments increase the financial burden on families and carers, but the assessments or alternative treatment may not always be appropriate.

## Continence and social care

NICE guidance urges commissioners and providers to deliver “care provision in an integrated way”, meaning that continence services should be accessible through primary, secondary care and care home settings.

NHS national guidance states that “care homes and commissioners should collaborate with each other to ensure adequate provision and funding of products”, and a [guide from the Royal College of Nursing](#) on continence care in care homes says that “putting a care plan in place and reviewing the care delivered is essential”.

However, what we've heard would suggest that continence care is not currently integrated with social care in a way that works for people. Since continence care is funded and delivered by the NHS, an individual assessment must be requested separately from the personal care assessment conducted by the council for all other aspects of social care. This means that someone's social care plan and continence care plan are not necessarily considered together.

Assessments for continence care should be integrated as an element of social care assessments and should include questions around whether people have had a continence care need in the past or can expect to in the future. This approach will avoid additional work and result in care plans taking enough account of people's broader needs.

# Spotlight on experiences



# Diverse ethnic communities

8,110 people's experiences informed this section

## Why is this issue important?

Providing excellent care for everyone is not possible without dealing with the inequalities that affect people's access to and experiences of health services.

It is therefore important to collect the views of a diverse range of people to identify what works well and what needs to improve. Our evidence highlights some of the particular challenges that people from diverse ethnic communities can face when using health and social care services.

## What have people told us?

### Services don't understand diverse cultural needs

People have told us how important it is for health and social care professionals to understand their individual cultural needs. For example, expectant parents wanted personalised maternity care plans to include the cultural customs or religious practices they wanted to observe.

#### Personal story: I can't access appropriate support

"A father from a Traveller community has been diagnosed with terminal bowel cancer and desperately needs a portaloos by the caravan. He cannot have a toilet in the caravan due to his cultural beliefs that this is not acceptable. Local services have said they cannot help. The family do not have much income and the father is currently undergoing chemotherapy. His need for a portaloos is desperate."

Healthwatch Essex

People have also told us how they have experienced negative attitudes and felt stereotyped by healthcare professionals, especially in the Gypsy, Roma and Traveller community. These experiences make it difficult for them to trust the healthcare system, deter them from seeking help and can impact on their health.

It is also important that services do not assume people's cultural needs can be understood and met by 'lumping together' people from diverse Black, Asian and Minority Ethnic backgrounds. Not everyone wants to engage with services in the same way.



Similarly, young people from refugee groups have told us their parents' experiences and expectations are usually very different from their own.

People's age, gender and personal preferences play a big part. To better meet people's needs, health and social care professionals need to treat everyone as an individual.

### **Services need to deal with communication barriers**

People consistently tell us about the communication barriers they face when accessing services, that make it harder for them to get the care they need.

Although patients should *always be offered a registered interpreter*, this service is often not available, making it hard for people to communicate about their health with professionals. Often people must depend on family members or friends to translate for them, sometimes leading to inaccurate translations or stigma when people disclose their health concerns. This can stop people from sharing all the relevant information with their healthcare professional, which could lead to inappropriate advice or treatment.

As well as problems with interpreting services, there are other communication barriers people face, such as:

- Information leaflets and posters are not always available in all the languages people need.
- Information leaflets use formal language to explain clinical terms, instead of simple language that mirrors how people speak.
- People with limited literacy do not always get extra support to fill in forms or use touchscreen appointment systems.
- Online services can be difficult to use for people who find it hard to read or write in English.

### **What can services do meet people's communication needs?**

Services should work with people to establish the best way to communicate with them, so they are actively involved in their care. For example, people with limited English have told us they find it easier to make GP appointments face-to-face, rather than over the phone or online.



**Personal story: Providing personalised care**

“Someone told us they had recently been in hospital and commented that they were very good, because they provided them with an Arabic translator over the phone. When the person said they were not very good at English the staff had patience with them and used photos and pictures to help explain things. Staff also used Google translate to help communicate with them. Because the staff took time with the person, they felt relaxed rather than nervous.”

Healthwatch North Somerset

**Challenges for people who are new to the country**

People who are refugees or recent migrants to the UK have told us about the barriers they face when using health and care:

- There is a lack of information about services and support for their health.
- They are worried they will be refused care or that receiving treatment will lead to future immigration applications being denied.
- Getting to healthcare services is difficult if they cannot afford to pay for transport.
- They are worried about raising concerns about their care if they have insecure immigration status.

Refugees and recent migrants are also worried they will be unable to pay for any care. Most non-EEA citizens must pay an annual fee of between £150 and £400 to access healthcare through the NHS. This charge is usually paid as part of an immigration application for a visa. The charge was introduced in 2015, and the fee was then doubled in January 2019.

People seeking hospital treatment deemed ‘non-urgent’ are also required to pay for their treatment upfront if they do not have indefinite leave to remain; this includes asylum seekers. Hospitals are responsible for assessing whether patients are eligible for free treatment by asking people for proof of their leave to remain in the UK. This can lead people to delay seeking treatment if they fear that they will not have the correct documentation.

**How can services better support refugees and vulnerable migrants?**

To reduce people’s worries about using services and to improve their knowledge of the support available, healthcare professionals need to provide accurate, understandable information about local health and social care services.

## Our findings within the wider context

The way NHS services and local authorities plan does not always consider the barriers faced by different groups.

A recent [Women and Equalities Committee](#) inquiry into the inequalities faced by Gypsy, Roma and Traveller communities highlighted how Joint Strategic Needs Assessments (JSNAs) rely heavily on statistical information, which is lacking for these communities.

This is because these groups are often left out from data collection; for example, there is no standard category for Gypsy, Roma and Traveller in the NHS Data Dictionary.

This means that many JSNAs do not think about the needs of this group, even in places which have large Traveller communities.

By collecting data on ethnicity, the system can better understand whether certain groups are experiencing poorer care. It also helps to find out how changes to health and social care services impact on equality.

The approach taken by the NHS does not match other national data sources like the census, which has had a category for Gypsy, Roma and Travellers since 2011. With another census occurring in 2021, now is a good moment for the NHS to ensure the demographic data it captures is matched with other sources that drive so many public policy decisions.

The Equality and Human Rights Commission (EHRC) has produced a [measurement framework](#) which can be used by any organisation to monitor progress on equality and human rights. The framework recommends breaking down indicators by a standard set of protected characteristics like gender, disability or ethnicity. The NHS should collect demographic and equalities data in line with the EHRC framework to support local and national understanding of population inequalities and health needs.

In our last [quarterly report](#), we also highlighted how the lack of data sharing across the NHS is a consistent source of frustration for people. Improved data sharing should ensure that digital records flag people's needs, and reasonable adjustments are automatically put in place when they use health services.